Dear State Representative:

Major birth defects affect approximately 1:33 babies born in the United States. ¹ Spina bifida is but one of the defects affecting the brain and spinal cord, occurring in about 1:2858 births.

Some defects are much more common than spina bifida: heart malformations. Heart defects, occur in about 1:100 live births. Of babies with heart malformations, about a quarter are severe enough to require intervention in the first year of life. Another common defect, cleft lip with or without cleft palate (1:940 births), also requires intense multidisciplinary intervention soon after birth.

Many fetal defects can be identified prior to birth; some cannot. Spina bifida is one problem that usually can be identified prior to birth. Existing protocols in the obstetric community outline counseling and care strategies. These protocols are frequently reviewed, and can rapidly change with advances in testing, treatment and technology. Please see the American College of Obstetrics and Gynecology (ACOG) Practice Bulletin.²

Most birth defects cannot be prevented as they are the product of factors that we do not fully understand, let alone have the ability to control. Spina bifida is one of the few defects which can be prevented at least partially, with PREPREGNANCY folic acid (vitamin B9) supplementation.³

This proposed legislature is simply not helpful. It singles out just one of many defects that children are born with every day. This law is an unnecessary, redundant, and heavy-handed intrusion of government into the ever-changing practice of medicine. Guidelines for care, based on evolving understanding and technology are already available: if providers do not adhere to existing standards, there are legal channels to address deviance.

The birth of a child with a birth defect can be devastating to parents. Preparation and counseling is important, when possible, to lessen the shock and prepare for what is to come. This law does nothing the help this process, unduly shifts attention to just one of many birth defects, and risks fixing in place perspectives on spina bifida that exist at this moment in time.

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